EPF Background Brief: Patient Empowerment

15/05/2015

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1 Introduction

The purpose of this short briefing paper is to clarify the concept of patient empowerment and related concepts, as they are used by the European Patients' Forum (EPF) in our campaign 2015-16.[1] The aim of this paper is to help create a common understanding, rather than present one 'definitive' definition.

This paper was developed in consultation with the EPF internal Working Group on Patient Empowerment and the Steering Group of the conference and campaign; it is not a formal policy position statement of the European Patients' Forum. The paper will be revised and further developed in the course of the campaign, and may then undergo a formal membership consultation.

2 The policy context

Patient empowerment is at the root of EPF's vision and mission, as reflected in our Strategic Plan 2014-2020:

> **Goal 4: Patient Empowerment**
> To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their condition according to their preference, whilst raising awareness about their rights and responsibilities.

Chronic diseases are seen as a sustainability challenge for European health systems. This is usually presented in terms of funding – our health systems cannot cope financially with chronic conditions and the ageing population.

But from a patient's perspective, the health systems are often unable to cope well with chronic conditions *because they do not meet patients' needs*.[2][3]

Financing of the health system plays a role (e.g. chronic underfunding, lack of adequate numbers of healthcare professionals…), but often the system challenge has more to do with the way healthcare is delivered and services organised: fragmentation of care is a major problem for patients, who often have to "fight the system" just to get the care they need.

Chronic disease requires a fundamental shift from disease-centred to patient- and family-centred approach, combining self-management in the community with well-integrated professional support through the life-course. This implies the empowerment of patients and their involvement at every level in the health system, ensuring active patient involvement in policy-making and in co-designing of care services to meet their needs more effectively.

EPF's campaign aims to promote understanding of what patient empowerment means *from the patient perspective*. We want to raise awareness among political decision-makers and stakeholders of

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[1] http://www.eu-patient.eu/Events/upcoming-events/conference-on-patient-empowerment/

[2] See for example EPF paper on chronic diseases (2012) and healthy and active ageing (2011).

[3] "Patients" is used in this paper for brevity, but it should be taken to include the whole family.

the concept of empowerment and commit them to concrete activities to promote the empowerment and meaningful involvement of patients as equal and respected partners.

3 Defining patient empowerment

3.1 EMPOWERMENT OR INVOLVEMENT?

The difficulty with defining patient empowerment in a way that is understandable to everyone is that it is essentially a rather abstract, intangible concept. It is also not easy to distinguish clearly between patient empowerment and patient involvement. In certain contexts such as research, the term patient engagement is also often used.

However, if we think of "involvement" as similar to "participation", the distinction becomes clearer. In very simplified terms, empowerment is an intangible process, which often manifests itself in concrete action. The term participation may also be preferable because it is always an active word (in English).[4]

For example, when a patient gains all the knowledge s/he needs to understand her/his condition, her/his life goals and the benefits and risks of different therapeutic options, s/he can reflect what therapeutic choice will be most suitable in her personal situation (empowerment), and participate actively in the therapeutic decision-making process with her/his doctor (involvement).

3.2 EPF'S DEFINITION OF PATIENT EMPOWERMENT

EPF uses the following definition of empowerment developed for the EU Joint Action on Patient Safety and Quality of Care (PaSQ):

> Empowerment is "a multi-dimensional process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important." Collective empowerment is "a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs." [5]

Empowerment is therefore a process through which people increase their capacity to draw on their personal resources in order to live well with chronic conditions in their daily life, as well as navigate the health care environment. Aspects of empowerment include self-efficacy, self-awareness, confidence, coping skills, health literacy, etc. (see "Related concepts", p.7).

Empowerment is not a simple process, nor is it necessarily linear. A patient can feel empowered in a certain context, and disempowered in another. During the "patient journey", her/his feeling of being empowered can change according to the people and structures that she/he comes into contact with.

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[4] It is possible to say "I involve you", which leaves the involved person in a passive position. But it is not possible to say "I participate you".

[5] PaSQ, adapted from Luttrell et al. 2009 and the Duque project (www.duque.eu)

3.3 EPF'S DEFINITION OF PATIENT INVOLVEMENT

In the PaSQ Joint Action, patient involvement is defined as follows:

> Individual: the extent to which patients and their families or caregivers, whenever appropriate, participate in decisions related to their condition (e.g. through shared decision-making, self-management) and contribute to organisational learning through their specific experience as patients.
>
> Collective: the extent to which patients, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation, design and delivery.

Involvement/participation therefore has both an individual and a collective dimension. Patient involvement whether individually or collectively can take place micro, meso and macro levels. For example: at individual (micro) level, patients can participate through shared decision-making and self-mangement. At organisation (meso) level, patients can participate by being involved in quality improvement initiatives at hospitals. At policy (macro) level, patient organisations participate in shaping health policy.

3.4 THE "EMPATHIE DEFINITION": EMPOWERMENT AND INVOLVEMENT

Recently, the EU-funded EMPATHIE project ("Empowering Patients in the Management of Chronic Diseases") developed the following working definition of *an empowered patient*. This definition in fact combines both empowerment and involvement: to show this we have highlighted in green words related to empowerment, and in purple words related to involvement:

> "An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behaviour and to work in partnership with others where necessary, to achieve optimal well-being.
>
> Empowerment interventions aim to equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions related to their condition to the extent that they wish to do so; to become "co-managers" of their condition in partnership with health professionals; and to develop self-confidence, self-esteem and coping skills to manage the physical, emotional and social impacts of illness in everyday life." [6]

3.5 DISCUSSION

The main drawback of the EMPATHIE definition is that it focuses only on the individual patient and its scope is limited to managing life with a chronic condition, even though it does go beyond the purely medical context. It does not include the notion of "critical awareness" and patients' active participation with the aim of changing the system.[7] It also does not address the role of patient organisations as representatives of the patient community in a wider sense whose role is to advocate for the patient perspective at policy level.

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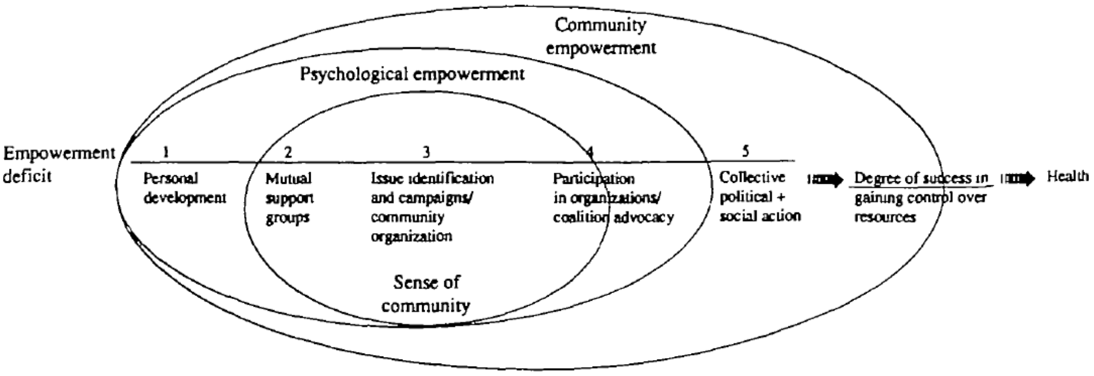
[6] EMPATHIE Summary Report, 30 September 2014 available at http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf

[7] "Self-Management: A Background Paper". Patrick McGowan, PhD, University of Victoria – Centre on Aging. 2005, p. 3

The EPF definition of empowerment highlights the collective dimension of empowerment and the importance of (political) action towards change: "…a process through which individuals and communities are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs." The overlapping spheres of personal and community empowerment can be illustrated by this scheme by Christopher Rissel:



Source: article "Empowerment: the holy grail of health promotion?", Christopher Rissel[8]

From EPF's point of view it is important to bear in mind the collective dimensions of empowerment and the importance of patients' involvement in health policy and service design as a patient community, whose aim is to change the system to work better for (individual) patients and their families.

Empowerment can be seen as a philosophy or vision, as well as a strategy. It is also system issue – processes and structures can be seen as empowering if they enable people to gain knowledge and develop skills needed to problem-solve and make decisions, taking control to the extent that they wish. At the micro level (the individual patient), the healthcare professional is the most important contact point for the patient and the system; (dis)empowerment often manifests in the patient-professional relationship. At the meso level (organisation, e.g. hospital), the care delivery processes or the design of the environment can be (dis)empowering. At the macro level (policy), factors that contribute to (dis)empowerment can include information to patients or the lack of it, implementation of patients' rights laws, (lack of) opportunities for patients to participate in health policy, (lack of) transparency of the system, etc.

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[8] Rissel C (1994) "Empowerment: the holy grail of health promotion?" *Health Promotion International*, Vol. 9 No. 1, pp. 39-48. Oxford University Press, 1994.

3.6 IN A NUTSHELL

Empowerment is:

- A process (not static)
- Non-binary (there are degrees of empowerment)
- Non-linear (going 'back' as well as 'forward')
- Context-dependent
- Something that cannot be imposed by others, but can be facilitated
- Both individual (patient) and collective (the patient community).

4 Related concepts

4.1 MEANINGFUL PATIENT INVOLVEMENT

The Alma Ata declaration defined civic involvement in healthcare as both a right and a duty: "The people have *the right and duty to participate* individually *and collectively* in the planning and implementation of their healthcare." (Alma Ata Declaration – Principle IV. 1978, WHO)

"Meaningful patient involvement" as defined by EPF[9] is based on the premise that patients have a *specific expertise* derived from simply being patients, which is a valuable source of *experiential knowledge*. The patient's perspective is not the same as the lay/consumer perspective. The patient's knowledge is derived from living with a condition day-to-day and from being in frequent contact with the healthcare system.

Levels of meaningful involvement are often illustrated by the "ladder" model first developed by Arnstein in 1969[10] (left). This model has been variously adapted, including for patient involvement in research by the PatientParner project[11] (right).

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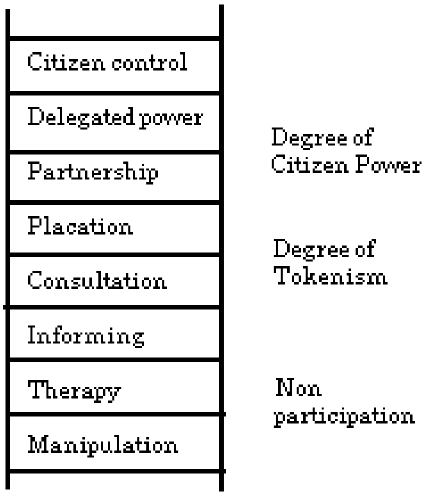
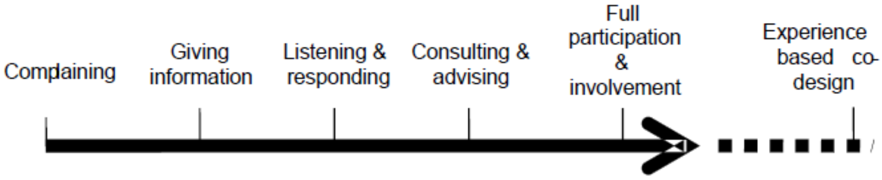
[9] "Patients *take an active role in activities or decisions that will have consequences for the patient community*, because of their *specific knowledge and relevant experience as patients*. The involvement must be planned, appropriately resourced, carried out, and evaluated as to its outcomes, impact and the process itself, according to the values and purposes of all participants." (EPF project "VALUE+", 2009).

[10] Arnstein, Sherry R. "A Ladder of Citizen Participation," *JAIP*, Vol. 35, No. 4, July 1969, pp. 216-224. Accessed at http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html

[11] PatientPartner (2010) project funded under EU FP7. www.patientpartner-europe.eu



The illustration below from Bate and Robert (2006)[12] shows how patient involvement, specifically in healthcare, can progress from rather passive involvement to active partnership:



In addition to being a right, patient involvement is recognised as having benefits for developing therapies and healthcare services in a way that benefits patients and society. EPF believes that meaningful patient involvement in health policy and programmes will lead to services that provide real value for patients, as well as reducing unnecessary services (waste). This is reflected in our strategic goal 3: Patient involvement. “To advance meaningful patient involvement in the development and implementation of health-related policies, programmes and projects in the EU.”[13]

4.2 HEALTH LITERACY

Health literacy is a key aspect of empowerment. Although empowerment involves much more than becoming an educated/informed patient, the right information and resources are fundamental tools for empowerment. Health literacy, however, is more than information. It is defined variously as:

> “The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.” (WHO, www.who.int)
>
> “The ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena.” (Kickbusch et al, 2005)

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[12] “Experience-based design: from redesigning the system around the patient to co-designing services with the patient” Bate P and Robert G, *Qual. Saf. Health Care* 2006; 15; 307-310.

[13] EPF Strategic Plan 2014-2020, p. 17.

> "People's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course." (Sorensen and Brand, 2013)

From a patient's perspective, the knowledge and competence gained through health literacy leads to the strength and empowerment needed to manage well a disease and its impacts on quality of life. Health literacy starts with good, easily understandable information: information is a tool towards improved health literacy.

To make genuinely informed decisions about their health and treatment, it is vital that patients can access all the relevant information needed to make those decisions, in an easily understandable format. The health literate patient is then able to process, appraise and apply the information to her or his own personal circumstances. This is usually defined as "functional" health literacy. More advanced levels of health literacy are "interactive" health literacy (cognitive, literacy and social skills that enable active participation in healthcare) and "critical" health literacy (the ability to critically analyse and use information to participate in actions that overcome structural barriers to health).[14]

Patients' information needs are diverse and vary according to age, socio-economic status, gender, beliefs, preferences and coping strategies, and according to their general literacy, first language, skills and abilities. Needs often change during the patient's journey, as does the "empowerment status" of the individual patient.

4.3 SELF-MANAGEMENT

Patients are "experts by experience". Their perspective on chronic disease is unique: patients live with the condition every day, learn to manage it themselves with support from healthcare professionals, and by necessity learn to navigate the health system in order to get the right care. Self-management is a key element of patient-centred care: in chronic conditions, the management of the condition is mostly handled by the patient at home and in the community, so in this sense patients already "self-manage".

Self-management can be understood as a partnership between patients and the healthcare team: the team should support patients in "living with" their illness and in managing the conditions and their physical, psychological, emotional and social impacts. Through self-management support, patients can develop the confidence, self-efficacy and skills to take control of their daily life and attain the greatest possible quality of life. This also helps to make the best use of all available resources by, for example, improving adherence, reducing hospitalisation and emergency visits, and improving health outcomes.

Self-management, therefore, does not mean leaving the patient to cope on their own. It is a holistic approach providing the appropriate support and tools according to each person's individual needs and preferences.

There are a number of theoretical models on self-management, including Bandura's self-efficacy theory. Self-efficacy "pertains to an individual's belief in their capacity to successfully learn and

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[14] Nutbeam D. "Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century". Health Promotion International, 2000, 15(3):259–267. Cited in WHO, 2008.

perform a specific behaviour. A strong sense of self-efficacy leads to a feeling of control and to the willingness to take on (and persist with) new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident about their ability to achieve their goal. Interventions for improving self-care should therefore focus on building confidence and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them."[15]

There are also many ongoing initiatives to promote self-management as an aspect of patient empowerment. The European Network on Patient Empowerment (ENOPE)[16], of which EPF is a member, includes organisations in several countries, some of which deliver evidence-based programmes on chronic disease self-management and capacity-building, based on the Stanford Model.[17]

4.4 SHARED DECISION-MAKING

At the heart of the empowerment approach is seeing the patient-professional relationship as a partnership of equals. Empowerment does not happen in a vacuum: it is a two-way process. The patient needs a counterpart in the "empowered health professional" who welcomes the patient's involvement and knows how to create an enabling healthcare environment.

"You have to learn about thousands of diseases, but I only have to focus on fixing what's wrong with ME! Now which one of us do you think is the expert?"

- The average patients' preferences differ from those of average doctors: so, if doctors decide for patients, patients do not get what they want.
- The preferences of doctors vary: so, if doctors decide for patients, what patients get depends on which doctor they have.
- Patients' preferences vary: so, the individual patient's preferences must be taken into account, otherwise many patients do not get what they want."[1]

All health professionals need to develop the necessary skills and attitudes to adapt to the new patient role, shifting from a paternalistic medical model to a collaborative model. Key barriers identified in the EMPATHIE study included lack of time/shortages of staff, and patients' lack of information – but attitudes of health professionals were seen as most important barriers by *all* stakeholders.

Some existing training tools exist, such as education framework developed by the EU-funded ABC project in 2011[18] which integrates many of the principles of patient-centred healthcare, including: recognising the patient as an individual; listening actively to the patient; communicating; defining

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[15] Coulter A, Parsons S, Askham J (2008) "Where are the patients in decision-making about their own care?" Policy brief, WHO for the European Observatory on Health Systems and Policies ; Ory M, Lorig K, et al, (2013). Medical Care, November 2013. P. 13.

[16] www.enope.eu

[17] http://patienteducation.stanford.edu/programs/cdsmp.html

[18] "Managing and Supporting Medication Adherence. A framework for the education and training of health professionals in Europe", www.abcproject.eu

objectives and purpose with the patient; exploring options and deciding together; and supporting the patient.

A number of tools exist also for patients, such as decision-aids intended to help patients weigh the benefits and potential harms of different treatment options. A recent Cochrane review found that when patients use decision aids they: improve their knowledge of treatment options, feel more informed and clear about what matters most to them, have more accurate expectations of benefits and harms, and participate more in decision-making. Patients also tend to choose less interventionist approaches to treatment.[19] In accordance with this finding, a recent study in Denmark found that 40% fewer patients opted for surgery (hip/knee replacement) after engaging in a shared decision-process with a video explaining all the options.[20]

5 Important issues to consider

What if patients do not want to be empowered?

It is important to recognise that empowerment cannot be imposed “top down” - although it can be facilitated. A patient may *choose not to* participate in decision-making, delegating this to health professionals. The same patient, in different circumstances, may wish to be more or less involved in the decision. Equally, a patient may opt not to receive any treatment, after a discussion of all the options.

Older patients and those with more severe, life-threatening conditions tend to be more likely to want to leave treatment decisions to the professional. Patients in acute situations, for example emergency hospitalisation, are less likely to be (able to be) actively involved than patients managing a chronic condition at home. There are also some cultural differences in perceptions of patient involvement.[21]

Some patients cannot even access basic healthcare, how could they even think about empowerment?

Equity of access and patient empowerment are closely interlinked. At the same time, there are real risks that empowerment approaches, if not carefully implemented, may exacerbate existing inequalities. Some groups and individuals may be more in need of empowerment than others, and “one size” is not likely to fit all needs.

EPF’s position is that equity and empowerment are both system issues: Health systems and services should be designed to be empowering for all users, including disadvantaged or socially excluded patients. Application of patients’ rights and human rights generally should be ensured, such as meaningful informed consent focusing on the patient’s ability to make meaningful choice, rather than

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[19] Stacey et al. (2014) “Decision aids for people facing health treatment or screening decisions” Cochrane review. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001431.pub4/abstract

[20] http://patientsikkerhed.dk/in-english/publications.aspx

[21] Coulter A, Parsons S and Askham J (2008) “Where are the patients in decision-making about their own care?” WHO Policy brief, pp. 3-4.

on legal protection of healthcare staff; effective mechanisms should be in place to ensure non-discrimination, both within the health system and outside the health system.[22]

EPF is developing with our membership a strategy to explore empowerment from the point of view of potentially vulnerable, socially excluded or marginalised groups, and to propose strategies for ensuring patient organisations are inclusive. At system level, health inequalities need to be addressed via a comprehensive "Health Inequalities in all Policies" approach, including targeted strategies (for example health literacy) for specific groups.

Does empowerment mean shifting the responsibility on to the patient?

The empowerment approach aims to realise the vision of patients as "co-producers" of health and as integral actors in the health system. Many patients would like to take more responsibility for their own health and care, given the opportunities and support to do so.

To achieve this, there is a need to support patients, inter-alia through high-quality information and health literacy, but also to equip health professionals with the necessary skills to work in partnership with patients. There should be no question of shifting responsibility *inappropriately* on the shoulders of patients (for example regarding safety).

Is empowerment about making patients into consumers?

Patient empowerment in EPF's view is not about reducing healthcare to a transaction or a consumer good. It is not about consumerisation of healthcare, and it is not about blaming individual patients for consuming a lot of healthcare resources, or using a lot of services, because they are ill.

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[22] See EPF's work on non-discrimination.

This report received funding under an operating grant from the European Union's Health Programme (2014-2020).